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LETTERS

PATIENTS' ROLES AND RIGHTS IN RESEARCH

Patients' roles in research: where is Africa?

James Ditai *PhD fellow*[1 2], Andrew Weeks *professor of international maternal health*[2]

[1]Sanyu Africa Research Institute, Hosted at Mbale Regional Referral Hospital, Pallisa Road, PO Box 2190, Mbale, Uganda; [2]University of Liverpool, Department of Women's and Children's Health, Liverpool Women's Hospital, Liverpool L8 7SS, UK

Patients' roles and rights in research are vital.[1] In Africa, the challenges are greater than in other parts of the world owing to the large educational and societal gap between researchers and patients. Researchers may study matters affecting patients categorised as "illiterate" or "literate but not emancipated" and whose life experience is atypical. This can lead to well meaning but misplaced research questions, unsuitable consent processes, and inappropriate protocol and outcomes for the local context.

There is an ongoing important mismatch between patients, clinicians, and researchers.[2] In women's health, researchers and funders in sub-Saharan Africa have prioritised maternal mortality and largely neglected infertility. But many rural women consider infertility to be the more pressing problem because of its dire social consequences, including marriage breakdown and social stigma. Their voice, however, is rarely heard.

Similarly, patient information sheets used in the informed consent process rarely have patient input leading to long and complex forms full of legal jargon, which can hide important information.[3 4] This is akin to the "small print" used by banks and computer companies, which is rarely read before signing or clicking "I agree." The public would be better served by independent advisers providing short summaries of the key controversial sections.

Our ongoing project assesses public involvement in women's health research in Uganda. Our preliminary findings show that women fare better with short, pictorial information on a flip chart than with the standard 6-7 pages of participant information. We are conducting a randomised trial to show this. We are also working with the James Lind Alliance[5] to develop a context specific approach to understanding important research questions with women and the public in Uganda. We would welcome the chance to work with *The BMJ* in progressing this important topic in Africa.

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Full response at: https://www.bmj.com/content/362/bmj.k3193/rr-7.

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j.ditai@safri.ac.ug